Agency for Healthcare Research and Quality
Advancing Excellence in Health Care

NATIONAL QUALITY MEASURES CLEARINGHOUSE

General

Title

Satisfaction of care for children with sickle cell disease (SCD): percentage of parents or guardians of children younger than 18 years of age identified as having SCD who responded, on a scale of 1 to 5, "satisfied (4)" or "very satisfied (5)" to a survey question regarding satisfaction with the care received in the emergency department, during the measurement year.

Source(s)

Quality Measurement, Evaluation, Testing, Review, and Implementation Consortium (Q-METRIC). Basic measure information: satisfaction with care in the emergency department for children with sickle cell disease. Ann Arbor (MI): Quality Measurement, Evaluation, Testing, Review, and Implementation Consortium (Q-METRIC); 2014 Jun. 38 p.

Measure Domain

Primary Measure Domain

Clinical Quality Measures: Patient Experience

Secondary Measure Domain

Does not apply to this measure

Brief Abstract

Description

This measure is used to assess the percentage of parents or guardians of children younger than 18 years of age identified as having sickle cell disease (SCD) who responded, on a scale of 1 to 5, "Satisfied (4)" or "Very Satisfied (5)" to the following survey question during the measurement year:

> In the past 12 months, on a scale of 1 to 5, how satisfied have you been with the care you/your child have received in the emergency room? (Response options: 1 [Not Satisfied at All], 2, 3, 4, 5 [Very Satisfied], N/A, Don't Know, Refused to Respond)

A higher proportion indicates better performance, as reflected by high parent/guardian satisfaction.

Rationale

Approximately 2,000 infants are born with sickle cell disease (SCD) in the United States each year, a condition that occurs predominantly in people of African and Hispanic descent. SCD is a chronic hematologic disorder, characterized by the presence of hemoglobin S. From infancy onward, this hemoglobin variant can lead to an array of serious medical conditions. Because children with SCD are urged to seek care as soon as complications arise, many will visit an emergency department with time-sensitive issues such as infection, fever, and pain. Based on these encounters, patients with SCD and their families have direct and relevant experience to offer regarding care received. Parent surveys provide a valuable mechanism by which to gather and reflect the patient/caregiver perspective back to providers. Providers, in turn, can use this information to improve practices and better support their pediatric patients as they face a challenging, complex disease. Examples of possible practice adjustments include providing patients and families in the emergency department with realistic time estimates and detailed discharge instructions. There are no existing quality measures for assessing satisfaction of care in the emergency department for children with SCD.

Evidence for Rationale

Quality Measurement, Evaluation, Testing, Review, and Implementation Consortium (Q-METRIC). Basic measure information: satisfaction with care in the emergency department for children with sickle cell disease. Ann Arbor (MI): Quality Measurement, Evaluation, Testing, Review, and Implementation Consortium (Q-METRIC); 2014 Jun. 38 p.

Primary Health Components

Sickle cell disease (SCD); patient experience; care satisfaction; emergency department (ED); infants; children; adolescents

Denominator Description

The eligible population for the denominator is parents or guardians of children younger than 18 years of age identified as having sickle cell disease (SCD) who responded to a survey question regarding satisfaction with the care received in the emergency department during the measurement year (January 1 to December 31) (see the related "Denominator Inclusions/Exclusions" field).

Numerator Description

The eligible population for the numerator is parents or guardians of children younger than 18 years of age identified as having sickle cell disease (SCD) who responded, on a scale of 1 to 5, "Satisfied (4)" or "Very Satisfied (5)" to a survey question regarding satisfaction with the care received in the emergency department, during the measurement year (January 1 to December 31) (see the related "Numerator Inclusions/Exclusions" field).

Evidence Supporting the Measure

Type of Evidence Supporting the Criterion of Quality for the Measure

A clinical practice guideline or other peer-reviewed synthesis of the clinical research evidence

A formal consensus procedure, involving experts in relevant clinical, methodological, public health and organizational sciences

One or more research studies published in a National Library of Medicine (NLM) indexed, peer-reviewed journal

Additional Information Supporting Need for the Measure

Sickle Cell Disease Prevalence and Incidence
Sickle cell disease (SCD) is one of the most common genetic disorders in the United States (U.S.) (Kavanagh et al., 2011). The National Heart, Lung and Blood Institute (NHLBI) (2002) estimates that 2,000 infants are born with SCD in the U.S. each year. SCD affects 70,000 to 100,000 children and adults in the U.S., predominantly those of African and Hispanic descent (Hassell, 2010).

Sickle Cell Disease Pathology and Severity
Vaso-occlusion (the sudden blockage of a blood vessel caused by the sickle shape of abnormal blood cells) is responsible for most complications of SCD, including pain episodes, sepsis, stroke, acute chest syndrome, priapism, leg ulcers, osteonecrosis and renal insufficiency (Steinberg, 1999). In addition, SCD can have hemolytic and infectious complications that result in morbidity and mortality in children with the condition (Kavanagh et al., 2011).

Sickle Cell Disease Burden in Daily Life
The effect of SCD on children and families is significant; severe pain episodes and hospitalizations restrict daily activities and reflect negatively on school attendance and performance, as well as on sleep and social activities (Lemanek, Ranalli, & Lukens, 2009; Alvim et al., 2005). Although medical management of SCD continues to improve over time, 196 children in the United States died from SCD-related causes between 1999 and 2002 (Yanni et al., 2009).

Sickle Cell Disease Cost
In a study of health care utilization among low income children with SCD between 2004 and 2007, 27% of these children required inpatient hospitalization and 39% used emergency care during a year. Of these children, 63% averaged one well-child visit per year and 10% had at least one outpatient visit with a specialist (Raphael et al., 2009). Patients with SCD use many parts of the health care system, incurring significant costs. In 2009, mean hospital charges for children with SCD and a hospital stay were $23,000 for children with private insurance and $18,200 for children enrolled in Medicaid (HCUPnet, Healthcare Cost and Utilization Project, 2012). Kauf et al. (2009) estimate the lifetime cost of health care per patient with SCD to be approximately $460,000.

See the original measure documentation for additional evidence supporting the measure.

Evidence for Additional Information Supporting Need for the Measure

Alvim RC, Viana MB, Pires MA, Franklin HM, Paula MJ, Brito AC, Oliveira TF, Rezende PV. Inefficacy of piracetam in the prevention of painful crises in children and adolescents with sickle cell disease. Acta Haematol. 2005;113(4):228-33. PubMed

Hassell KL. Population estimates of sickle cell disease in the U.S. Am J Prev Med. 2010 Apr;38(4 Suppl):S512-21. PubMed

HCUPnet. Healthcare Cost and Utilization Project. [Web site]. Rockville (MD): Agency for Healthcare Research and Quality; 2006-2009

Kauf TL, Coates TD, Huazhi L, Mody-Patel N, Hartzema AG. The cost of health care for children and adults with sickle cell disease. Am J Hematol. 2009 Jun;84(6):323-7. PubMed

Kavanagh PL, Sprinz PG, Vinci SR, Bauchner H, Wang CJ. Management of children with sickle cell disease: a comprehensive review of the literature. Pediatrics. 2011 Dec;128(6):e1552-74.

Lemanek KL, Ranalli M, Lukens C. A randomized controlled trial of massage therapy in children with sickle cell disease. J Pediatr Psychol. 2009 Nov-Dec;34(10):1091-6.

National Heart, Lung and Blood Institute (NHLBI). The management of sickle cell disease. 4th ed. Bethesda (MD): National Institutes of Health, National Heart, Lung and Blood Institute, Division of Blood Diseases and Resources; 2002 Jun. 188 p.

Quality Measurement, Evaluation, Testing, Review, and Implementation Consortium (Q-METRIC). Basic measure information: satisfaction with care in the emergency department for children with sickle cell disease. Ann Arbor (MI): Quality Measurement, Evaluation, Testing, Review, and Implementation Consortium (Q-METRIC); 2014 Jun. 38 p.

Raphael JL, Dietrich CL, Whitmire D, Mahoney DH, Mueller BU, Giardino AP. Healthcare utilization and expenditures for low income children with sickle cell disease. Pediatr Blood Cancer. 2009 Feb;52(2):263-7. PubMed

Steinberg MH. Management of sickle cell disease. N Engl J Med. 1999 Apr 1;340(13):1021-30. PubMed

Yanni E, Grosse SD, Yang Q, Olney RS. Trends in pediatric sickle cell disease-related mortality in the United States, 1983-2002. J Pediatr. 2009 Apr;154(4):541-5. PubMed

Extent of Measure Testing

Reliability

Data and Methods. The testing data consisted of survey results from a sickle cell disease (SCD) health status assessment given to Michigan residents with SCD by the Michigan chapter of the Sickle Cell Disease Association of America (SCDAA), in conjunction with the Michigan Department of Community Health (MDCH) in an effort to document unmet needs. While the SCDAA ultimately will complete these surveys from among all persons with SCD in Michigan, the results presented here are based on a convenience sample of the SCD population.

Validity

Face Validity. Face validity is the degree to which the measure construct characterizes the concept being assessed. The face validity of this measure was established by a national panel of experts and advocates for families of children with SCD convened by the Quality Measurement, Evaluation, Testing, Review, and Implementation Consortium (Q-METRIC). The Q-METRIC expert panel included nationally recognized experts in SCD, representing hematology, pediatrics, and SCD family advocacy. In addition, measure validity was considered by experts in state Medicaid program operations, health plan quality measurement, health informatics, and health care quality measurement. In total, the Q-METRIC SCD panel included 14 experts, providing a comprehensive perspective on SCD management and the measurement of quality metrics for states and health plans.

The Q-METRIC expert panel concluded that this measure has a high degree of face validity through a detailed review of concepts and metrics considered to be essential to effective SCD management and treatment. Concepts and draft measures were rated by this group for their relative importance. This measure was highly rated: satisfaction with care in the emergency department received an average score of 7.7. A score of 9 represented the highest possible ranking.

Validity of Survey Data. This measure was tested using parent survey response data linked to Medicaid administrative claims to gauge the degree to which respondents had emergency department visits during the measurement year. Overall, 183 parents/responsible parties completed the health status assessment

survey; of those, a total of n=143 (78%) could be matched with Michigan Medicaid administrative claims. Among the n=143 of Medicaid beneficiaries, 60% had one or more claim for an emergency department visit during the measurement period.

Evidence for Extent of Measure Testing

Quality Measurement, Evaluation, Testing, Review, and Implementation Consortium (Q-METRIC). Basic measure information: satisfaction with care in the emergency department for children with sickle cell disease. Ann Arbor (MI): Quality Measurement, Evaluation, Testing, Review, and Implementation Consortium (Q-METRIC); 2014 Jun. 38 p.

State of Use of the Measure

State of Use

Current routine use

Current Use

not defined yet

Application of the Measure in its Current Use

Measurement Setting

Emergency Department

Hospital Outpatient

Managed Care Plans

Professionals Involved in Delivery of Health Services

not defined yet

Least Aggregated Level of Services Delivery Addressed

Single Health Care Delivery or Public Health Organizations

Statement of Acceptable Minimum Sample Size

Unspecified

Target Population Age

Age less than 18 years

Target Population Gender

Either male or female

National Strategy for Quality Improvement in Health Care

National Quality Strategy Aim

Better Care

National Quality Strategy Priority

Person- and Family-centered Care
Prevention and Treatment of Leading Causes of Mortality

Institute of Medicine (IOM) National Health Care Quality Report Categories

IOM Care Need

Living with Illness

IOM Domain

Effectiveness

Patient-centeredness

Data Collection for the Measure

Case Finding Period

The measurement year

Denominator Sampling Frame

Enrollees or beneficiaries

Denominator (Index) Event or Characteristic

Clinical Condition

Patient/Individual (Consumer) Characteristic

Denominator Time Window

not defined yet

Denominator Inclusions/Exclusions

Inclusions
The eligible population for the denominator is parents or guardians of children younger than 18 years of age identified as having sickle cell disease (SCD) who responded to a survey question regarding satisfaction with the care received in the emergency department during the measurement year (January 1 to December 31).

Note: Eligible parents or guardians are restricted to those with a child who has a positive, confirmed newborn screening result of SCD in the state newborn screening program records; acceptable SCD hemoglobin variants for screening results are listed in Table 2 of the original measure documentation, along with corresponding International Classification of Diseases, Ninth Revision (ICD-9) codes.

Exclusions
Children with a result in the state newborn screening records indicating one of the SCD variants listed in Table 3 of the original measure documentation (along with corresponding ICD-9 diagnosis codes), should not be included the eligible population *unless* there is also a positive, confirmed newborn screening result of SCD (refer to Table 2 of the original measure documentation).

Exclusions/Exceptions

not defined yet

Numerator Inclusions/Exclusions

Inclusions
The eligible population for the numerator is parents or guardians of children younger than 18 years of age identified as having sickle cell disease (SCD) who responded, on a scale of 1 to 5, "Satisfied (4)" or "Very Satisfied (5)" to a survey question (refer to Table 1 of the original measure documentation) regarding satisfaction with the care received in the emergency department, during the measurement year (January 1 to December 31).

Exclusions
Unspecified

Numerator Search Strategy

Fixed time period or point in time

Data Source

Patient/Individual survey

Type of Health State

Does not apply to this measure

Instruments Used and/or Associated with the Measure

Computation of the Measure

Measure Specifies Disaggregation

Does not apply to this measure

Scoring

Composite/Scale

Rate/Proportion

Interpretation of Score

Desired value is a higher score

Allowance for Patient or Population Factors

not defined yet

Standard of Comparison

not defined yet

Identifying Information

Original Title

Satisfaction with care in the emergency department for children with sickle cell disease.

Measure Collection Name

Sickle Cell Disease Measures

Submitter

Quality Measurement, Evaluation, Testing, Review, and Implementation Consortium (Q-METRIC) - Academic Affiliated Research Institute

Developer

Quality Measurement, Evaluation, Testing, Review, and Implementation Consortium (Q-METRIC) - Academic Affiliated Research Institute

Funding Source(s)

This work was funded by the Agency for Healthcare Research and Quality (AHRQ) and the Centers for Medicare & Medicaid Services (CMS) under the CHIPRA Pediatric Quality Measures Program Centers of Excellence grant number U18 HS020516.

Composition of the Group that Developed the Measure

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Financial Disclosures/Other Potential Conflicts of Interest

Unspecified

Adaptation

This measure was not adapted from another source.

Date of Most Current Version in NQMC

2014 Jun

Measure Maintenance

Unspecified

Date of Next Anticipated Revision

Unspecified

Measure Status

This is the current release of the measure.

The measure developer reaffirmed the currency of this measure in January 2016.

Measure Availability

Source available from the Quality Measurement, Evaluation, Testing, Review, and Implementation Consortium (Q-METRIC) Web site . Support documents are also available.

For more information, contact Q-METRIC at 300 North Ingalls Street, Room 6C08, SPC 5456, Ann Arbor, MI 48109-5456; Phone: 734-232-0657; Fax: 734-764-2599.

NQMC Status

This NQMC summary was completed by ECRI Institute on January 19, 2015. The information was verified by the measure developer on February 11, 2015.

The information was reaffirmed by the measure developer on January 7, 2016.

Copyright Statement

Production

Source(s)

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